Public Health Data Strategy

Public Health Data Goals and 2-Year Milestones

April 2023



Executive summary

The Public Health Data
Strategy (PHDS) outlines the
data, technology, policy,
and administrative actions
essential to exchange
critical core data efficiently
and securely across
healthcare and public health.

The strategy is designed to describe a path to address gaps in public health data, helping the nation become response-ready, promote health equity, and improve health outcomes for all.



To advance core public health missions (Detect and Monitor, Investigate and Respond, Inform and Disseminate, and Be Response-Ready), the PHDS addresses the <u>CDC Moving Forward</u> imperative to consistently deliver public health information and guidance to Americans in near real-time.

Through the PHDS, public health decision-makers (e.g., the public; labs; providers; other healthcare partners; state, tribal, local, and territorial health departments; CDC programs; federal agencies) will have a **clear**, **streamlined vision** of near-term priorities.



The Public Health Data Strategy outlines four Public Health Data Goals:

- 1. Strengthen the core of public health data¹
- Accelerate access to analytic and automated solutions to support public health investigations and advance health equity
- 3. Visualize and share insights to inform public health action
- 4. Advance more open and interoperable public health data

Accomplishing 2-year milestones associated with these goals **requires collaboration and partnership** with state, tribal, local, and territorial health departments; healthcare partners; and other federal agencies.



CDC will **create accountability** for these Public Health Data Goals and 2-year milestones through the **new Office of Public Health Data, Surveillance, and Technology (OPHDST)**, which will lead and strengthen engagement and collaboration with jurisdictions, CDC programs, and private partners, and focus the execution of data modernization activities.

^{1.} Ensure Core Data Sources are more complete, timely, rapidly exchanged, and available to support the integrated ability to detect, monitor, investigate, and respond to public health threats

What the Public Health Data Strategy (PHDS) is and why it matters Public Health Data Goals and 2-year milestones How CDC will help achieve these goals and milestones

What the Public Health Data Strategy is

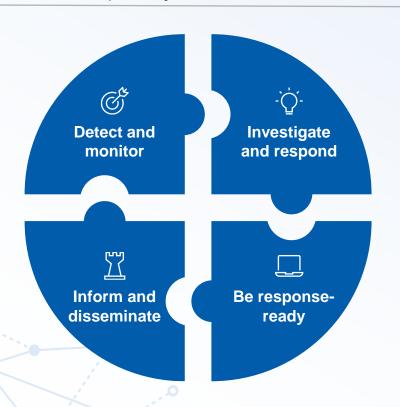
The Public Health Data Strategy (PHDS) outlines the data, technology, policy, and administrative actions essential to exchange critical core data efficiently and securely across healthcare and public health.

The strategy is designed to describe a path to address gaps in public health data, helping the nation become response-ready, promote health equity, and improve health outcomes for all.



Why the Public Health Data Strategy matters

To advance core missions of robust public health data aimed at improving health outcomes equitably...



...the Public Health Data Strategy ...



Addresses the **imperative of the CDC Moving Forward effort** to consistently deliver public health information and guidance to Americans in near real-time



Builds on **lessons learned from the COVID-19 pandemic** and other recent public health threats to be more response-ready



Aligns data modernization efforts at all levels of public health and across partners, focusing on near-term priorities



Measures success with specific 2-year milestones



Creates accountability for public health data with CDC's newly established Office of Public Health Data, Surveillance, and Technology

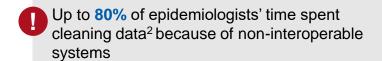
Source: CDC Moving Forward website

The Public Health Data Strategy aims to address challenges currently experienced across healthcare and public health

ILLUSTRATIVE

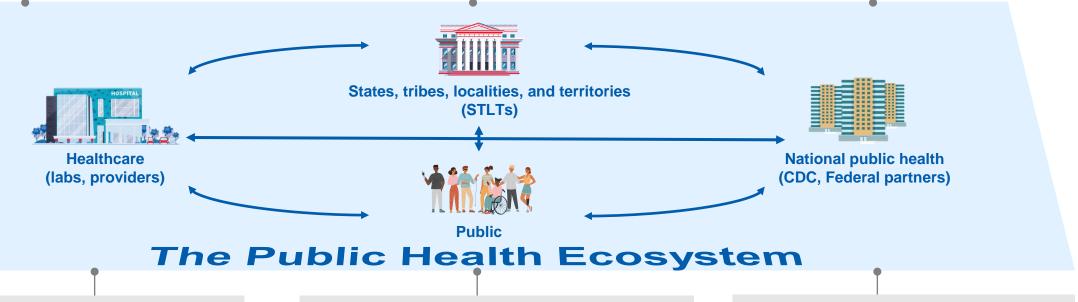


~70% of healthcare organizations using fax to send or receive care records¹





30%+ of COVID-19 cases missing data on race and ethnicity early in the pandemic³



6+ months often needed to develop and potentially rework Data Use Agreements⁴

- 12+ months for data on some reportable conditions to become available in national datasets or be disseminated in accessible and interoperable formats⁴
- ~3 months between first reported domestic mpox case and CDC data access agreements with STLTs⁵

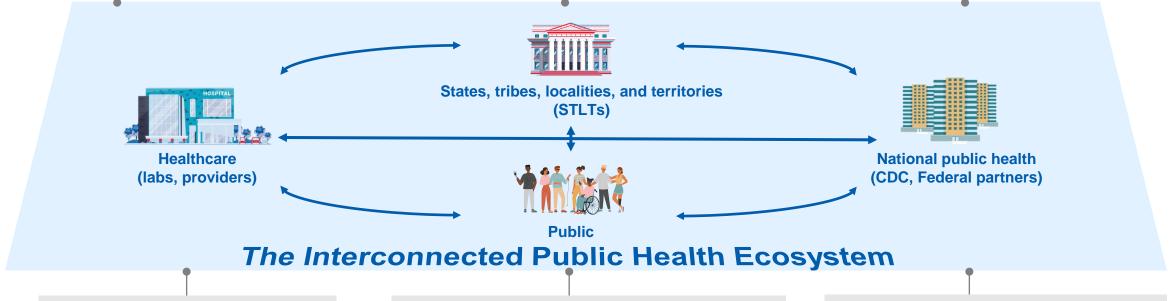
^{1.} ONC Data Brief No. 54 (2021), 2. 'A Prototype of Modernized Public Health Infrastructure for All: Findings from a Virginia Pilot' – CDC (2022), 3. CDC case surveillance data (as of Sept 9, 2022), 4. Average estimates by CDC staff, 5. 'Very Harmful' lack of data blunts U.S. response to outbreaks' – New York Times 2022

Successfully achieving the Public Health Data Goals and 2-year milestones addresses critical public health challenges by 2025

ILLUSTRATIVE

- Increased ability for STLTs to automatically exchange data with CDC creates a reliable national common operating picture
- Time saved on data cleaning and analytics, through reusable technologies, enables epidemiologists to focus on core public health missions
- Data on demand enables health disparities analysis across geographies, conditions, and settings

Public health data goal supported ←→→ High-level data flow



Faster sharing of data through language and terms for data protection and use

- American public has near real-time awareness of the status of high-consequence diseases through a centralized data dissemination platform
- <7 days needed to detect a suspected disease outbreak and begin nationwide monitoring</p>

The Public Health Data Strategy supports partners across the public health ecosystem

The Public Health Data Strategy will help...



The Public



Healthcare (labs and providers)



STLTs1



CDC programs



Federal agencies

...To...

Have greater access to critical information on public health emergencies, risks, trends, and resources

Identify and adopt ready-to-use tools that enable easier and faster sharing of critical core public health data

Prioritize data and technology investments to enable the most critical public health systems to be scalable, flexible, interoperable, sustainable, reusable, and intuitive

Streamline ongoing and planned efforts to support measurable and concrete 2-year milestones

Understand where and how to access richer public health data on demand to inform decision-making

greater
response
readiness
and
progress
toward
health

equity

Enabling

1. STLT: States, Tribes, Localities, and Territories

8

Public Health Data Strategy strengthens the core of public health data

Core Data Sources¹ are essential to identify diseases and conditions, detect emerging public health threats, and understand disease burden and severity across different populations. The PHDS decreases the burden to securely report these critical data and improves dissemination to ensure the right data are available at the right time.

Core Data Sources...

Case Lab **Emergency** dept. Vital stats. Immunization Healthcare capacity

Case data represent comprehensive disease and condition information used by public health to understand disease burden, know who is at risk, and identify outbreaks

Laboratory data, including test results and test type, enable public health agencies to track disease trends and identify outbreaks or exposures, and help frontline providers diagnose and treat health conditions

Emergency department data, including clinical diagnoses, signs, and symptoms, help identify near real-time trends for new, emerging, and developing public health threats to inform faster detection and response

Vital statistics data include birth and death data and are essential to understand disease severity, mortality, trauma, and toxicity that might signal a larger public health emergency

Immunization data capture vaccine doses administered (both routinely recommended and response-related) to support calculating vaccination coverage levels and trends

Healthcare capacity and utilization data assess availability of healthcare resources, including staff, beds, and equipment, aiding understanding of health system stresses and disease severity to inform resource allocation

^{1.} Core Data Sources as defined in CDC Advisory Committee to the Director (ACD) <u>Data and Surveillance Workgroup (DSW) Report</u>; non-exhaustive of all data sources critical to public health awareness and response (e.g., advanced molecular detection data)

What the Public Health Data Strategy (PHDS) is and why it matters

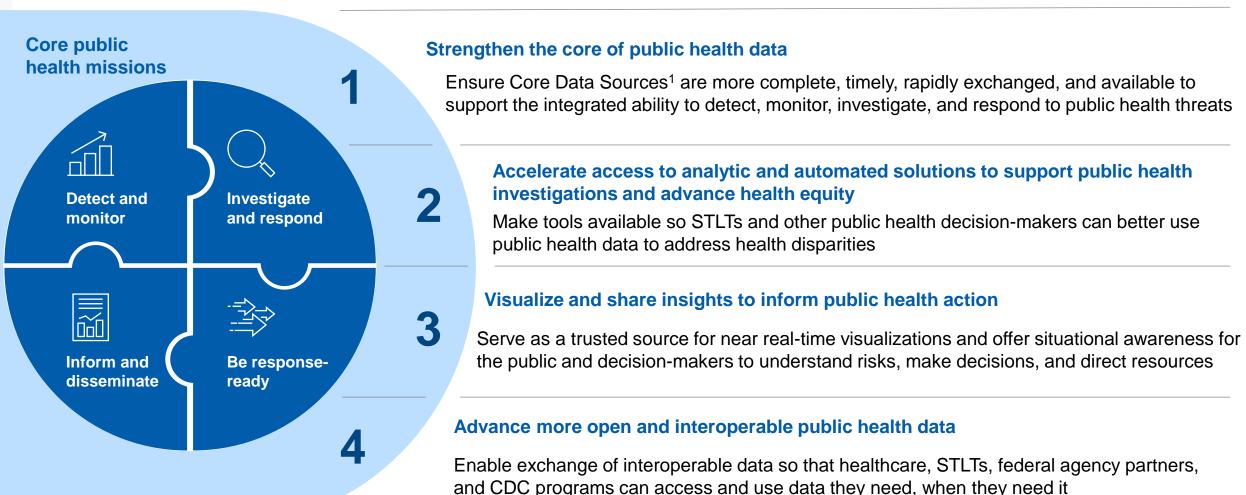
Public Health Data Goals and 2-year milestones

How CDC will help achieve these goals and milestones



Four major Public Health Data Goals enable the core public health missions

Public Health Data Goals



^{1.} Case (including electronic case reporting [eCR]), lab (including electronic lab reporting [ELR], Electronic Test Orders and Results [ETOR]), emergency department (including National Syndromic Surveillance Program [NSSP] emergency department data), vital statistics, immunization, healthcare capacity (including National Healthcare Safety Network [NHSN] data)

Public Health Data Goals drive key outcomes over the next 2 years

ILLUSTRATIVE

Goals

By the end of 2024, 2-year milestones strive to ensure...

SPECIFIC MILESTONES BY YEAR ON FOLLOWING PAGES

- Strengthen the core of public health data
- States, tribes, localities, and territories (STLTs) have reduced reporting burden as case data are electronically reported in a consistent format, using a CDC Front Door concept
- Public health labs can forecast needs better with integrated, electronic ability to see test orders before samples arrive and ensure faster exchange of orders and test results with submitters
- STLTs can access lab reports more quickly and through multiple pathways, enabling faster public health action (e.g., case investigation, contact tracing)
- CDC can access lab, case, and mortality data faster, enabling robust situational awareness that informs decision-making across the nation
- STLTs and CDC programs have access to more early warning signals from emergency departments (EDs), with up to 80% participation by US non-federal EDs in the National Syndromic Surveillance Program (NSSP)
- Accelerate access to analytic and automated solutions to support public health investigations and advance health equity
- STLTs and CDC can identify emerging threats in all parts of the nation in a timely way as more critical access hospitals in rural communities send case data electronically
- STLTs can address gaps in the public health workflow such as linking case, lab, and immunization records to enrich data and inform public health action through reusable technologies
- STLTs and communities can **identify**, **prevent**, **and mitigate disproportionate impact on populations** through use of automated reports provided by CDC, using CDC public health databases
- Wisualize and share insights to inform public health action
- STLTs and CDC programs receive quicker access to data and insights from Core Data Sources¹
- Americans can access near real-time data and visualizations made available via a centralized data dissemination platform (e.g., a Public Health Data Channel like the National Weather Service) to improve understanding and inform decisions about public health risks
- Advance more open and interoperable public health data
- CDC establishes a strategic **pathway of data exchange with providers' electronic health records (EHRs)** through at least 2 initial Trusted Exchange Framework and Common Agreement (<u>TEFCA</u>) for public health use case pilots
- CDC and STLTs increase data exchange back to healthcare providers, helping to inform clinical decision-making
- Data use and access are easier through established, standardized agreements (e.g., for sharing emergency department data with CDC programs, STLTs), enabling quicker access to minimal data necessary for response during a public health emergency
- CDC has measurably and securely increased the number of accessible open public health data sets for timely use and faster insights

Accomplishing the Public Health Data Goals requires collaboration and partnership with STLTs, healthcare partners, and other federal agencies

Success is measured by 2-year milestones (for Goal 1)

Public Health Data Goal

Milestones within 2 years¹

Strengthen the core of public

core of public health data
Ensure Core Data
Sources² are more complete, timely, rapidly exchanged, and available to support the integrated ability to detect, monitor, investigate, and respond to public health threats

End of 2023

STLTs enabled to submit a generic **core case data feed** that can be used for national disease notification



32 jurisdictions³ are ingesting <u>eCR</u> data into disease surveillance systems



90% of <u>ELC</u> recipients are connected to one or multiple intermediaries (e.g., AIMS, ReportStream, HIEs) for <u>lab</u> data



90% of State Public Health Labs have implemented <u>ETOR</u> (e.g., web portal, direct integration, or use of intermediary) with at least 1 healthcare partner for at least 1 lab program



75% of CDC infectious disease labs send **lab test results** to external partners electronically (e.g., using ELR, CSTOR, intermediary)



Reduced time to send mortality data to and receive coded cause of death data from CDC for 12–15 jurisdictions³ through use of FHIR messaging



CDC receives and ensures access to commercial lab data from at least **2 major national commercial labs** to enable situational awareness across multiple conditions

End of 2024



Core case data for select nationally notifiable conditions are reported using a common format, using a <u>CDC Front Door</u> concept, and shared back in near real-time for CDC programs and STLT partners to access



38 jurisdictions³ are ingesting eCR data into disease surveillance systems



Almost 100% of <u>ELC</u> recipients are connected to multiple intermediaries (e.g., AIMS, ReportStream, HIEs) for <u>lab</u> data



100% of State Public Health Labs have implemented <u>ETOR</u> (e.g., web portal, direct integration, or use of intermediary) with at least 1 healthcare partner for at least 1 lab program



50% of **lab test order** requests received electronically at CDC infectious disease labs (e.g., using ETOR, CSTOR, intermediary)



Reduced time to send mortality data to and receive coded cause of death data from CDC for 30 additional jurisdictions (42–45 total)³ through use of FHIR messaging



CDC receives and ensures access to commercial lab data from at least 3 major national and regional commercial labs to enable situational awareness across multiple conditions



Increased participation to 80% (from 73% today) of U.S. non-federal emergency departments to increase representativeness of NSSP data sources and users

Potential impact: <7 days needed to detect a suspected disease outbreak and begin nation-wide monitoring, through using faster case, lab, emergency department, mortality data

Success is measured by 2-year milestones (for Goal 2)

Public Health Data Goal

Milestones within 2 years¹

End of 2023

End of 2024

2

Accelerate access to analytic and automated solutions to support public health investigations and advance health equity

Make tools available so STLTs and other public health decision-makers can better use public health data to address health disparities



Critical access hospitals in production with eCR increased to 25%, up from 20% in 2022



Reusable technologies to link multiple data streams (e.g., case, lab) made available to all jurisdictions and deployed by at least 1 STLT – saving time for epidemiologists who currently spend up to 80% of their time on data cleaning²



Critical access hospitals in production with **eCR** increased to **35%**



Reusable technologies to link multiple data streams (e.g., case, lab) adopted by multiple STLTs



At least 2 automated reports using CDC's healthcare databases available within CDC and across STLTs to identify and address health disparities

Potential impact: Improved data available to epidemiologists (e.g., 2x critical access hospitals sending case data electronically), enabling faster health equity analyses

^{1.} Accomplishing the Public Health Data Goals requires collaboration and partnership with STLTs, healthcare partners, and other federal agencies

Success is measured by 2-year milestones (for Goal 3)

Public Health Data Goal

Milestones within 2 years¹

End of 2023

End of 2024

3

Visualize and share insights to inform public health action Serve as a trusted source for near realtime visualizations and offer situational awareness for the public and decisionmakers to understand risks, make decisions. and direct resources



Minimum viable product for centralized data dissemination platform developed in partnership with CDC's Office of Readiness and Response to share timely and data publicly



Data and visualizations available within 2–3 days (from 5–90+ days) for CDC programs and STLTs since time of receiving case data at CDC for at least 1 nationally notifiable condition (i.e., viral hepatitis)



Centralized data dissemination platform launched to streamline insights from case, emergency department, mortality data, and at least 1 other data source



Data and visualizations available within 2–3 days (from 5–90+ days) for CDC programs and STLTs since time of receiving case data at CDC for multiple nationally notifiable conditions

Potential impact: Faster, actionable insights available to the public in near real-time (2–3 days from 5–90+ days) through a centralized data dissemination platform

Success is measured by 2-year milestones (for Goal 4)

Public Health Data Goal

Milestones within 2 years¹

End of 2023



4

Advance more open and interoperable public health data Enable exchange of interoperable data so that healthcare, STLTs, federal agency partners, and CDC programs can access and use data they need, when they need it



CDC selects a QHIN and has identified at least 2 public health use cases for <u>TEFCA</u>, establishing a pathway for data exchange with healthcare systems and providers



Standard language and terms for data protection and use agreed upon with public health partners for Core Data Sources, consistent with ACD DSW recommendations



New data access agreement established to enable easier sharing of emergency department data from NSSP across STLTs and CDC programs



Minimal data elements necessary for public health response defined for at least case and lab data, in collaboration with STLT partners and CDC programs



CDC launches pilots for at least **2 public health use cases** with <u>TEFCA</u> (e.g., query data from healthcare settings for urgent public health investigations)



Data access and use under established language and terms across at least 15% of funded states and territories for Core Data Sources, including case data



At least 50% of existing NSSP jurisdictions adopt new data access agreement to enable easier sharing of emergency department data across STLTs and CDC programs



Minimal data elements necessary for public health response defined for **multiple data sources**, in collaboration with STLT partners and CDC programs



Number of public health data sets published by CDC with metadata utilizing FAIR open data principles increased by 10%

Potential impact: Standardized language and terms for data use introduced across healthcare and public health, enabling greater data quality and easier data sharing

What the Public Health Data Strategy (PHDS) is and why it matters Public Health Data Goals and 2-year milestones How CDC will help achieve these goals and milestones

How CDC will help achieve the Public Health Data Strategy goals and milestones



Increase engagement, collaboration, and continual feedback

Increase engagement and collaboration with:

- **STLTs:** Collaborate on and continually provide feedback on progress towards key 2-year milestones (e.g., DUAs, reusable technologies); engage directly with STLTs to understand priority needs
- Providers and labs: Gather feedback from the frontlines on how CDC can better support progress towards 2-year milestones
- CDC: Establish internal steering committee to provide guidance on longer term PHDS, monitor and provide input on progress; establish mechanisms to solicit programmatic input and identify priority needs
- Private partners: Organize Industry Days and promote data exchange pilots to work toward modernization together
- Federal agency partners: Collaborate with partners such as ONC and CMS to advance shared understanding of activities needed to support 2-year milestones, including TEFCA for public health



Establish accountable office within CDC

Ensure accountability for the Public Health Data Goals sits with CDC's Office of Public Health Data, Surveillance, and Technology (OPHDST):

- Structure the organization to support core public health missions
- Identify owners within OPHDST and across the agency to drive progress for specific 2-year milestones
- **Update the agency regularly** on Public Health Data Strategy goals and milestones

The Public Health Data Strategy is an ambitious but necessary plan to improve the exchange of core data across healthcare and public health.

Successful implementation of the strategy—and achievement of the Public Health Data Goals over the next two years—will require collaboration with STLTs, healthcare partners, and other federal agencies, as well as sustained resources.

List of terms used in this document

ACD	Advisory Committee to the Director (ACD), Centers for Disease Control and Prevention	
AIMS	Association of Public Health Laboratories (APHL) Informatics Messaging Services platform	
CSTOR	CDC Specimen Test Order and Reporting	
DMI	Data Modernization Initiative	
DSW	Data and Surveillance Workgroup (within the Advisory Committee to the Director)	
DUA	Data Use Agreement	
eCR	Electronic Case Reporting	
EHR	Electronic Health Records	
ELC	Epidemiology and Lab Capacity Cooperative Agreement	
ELR	Electronic Laboratory Reporting	
ETOR	Electronic Test Orders and Results	
FAIR	Findability, Accessibility, Interoperability, and Reuse (of digital assets)	
FHIR	Fast Healthcare Interoperability Resources	
HIE	Health Information Exchange	
NBS	NEDSS Base System	
NHSN	National Healthcare Safety Network	
NSSP	National Syndromic Surveillance Program	
OCIO	Office of the Chief Information Officer	
OKR	Objectives and Key Results	
PHDS	Public Health Data Strategy	
QHIN	Qualified Health Information Network	
SPHL	State Public Health Laboratory	
STLT	States, Tribes, Localities, and Territories	
TEFCA	Trusted Exchange Framework and Common Agreement	
		20